

HIV Testing

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I. Introduction

There is a continued need for high-quality, questionnaire-based data to develop and evaluate HIV, STD, and TB prevention/elimination programs. Self-reported behavioral data can compliment incidence and prevalence surveillance data in monitoring and anticipating the course of an epidemic. Questionnaire-based data related to HIV/STD and TB prevention is collected in a number of settings including general population surveys, behavioral surveillance systems of high-risk and infected populations, and as part of intervention studies. However, the necessary integration of data derived from these systems is often hampered by a lack of comparability between data items intended to measure the same behavior or concept.

The HIV-STD Behavioral Surveillance Working Group was formed in the fall of 1997 to address the need for comparable data across various data systems by developing and promoting the use of common questionnaire items related to HIV/STD/TB risk and prevention. The HIV-STD BSWG seeks to coordinate and enhance existing data systems and methods, in order to provide data for use of planning and evaluating prevention programs at the national, state, and local levels. The core items offered here on HIV Testing behaviors, as well as the Sexual Behavior and Drug-Related Risk core items, are the principal results of this effort.

The text preceding the core items provides a synopsis of the purpose, scope, and current development status of the core items for HIV Testing behavior. Interested readers are referred to Introduction to the Core Questions for a more detailed explanation of the rationale and methods used by the working group to produce the core items.

II. Purpose and Scope

Prevention planners and policy makers working at the national, state, and local level require timely, relevant, and representative HIV risk and preventive indicator data to develop rational and effective prevention programs and policies. There is wide consensus that the lack of coordination across questionnaire-based data collection

systems for these indicators precludes these systems from providing the information required. The core question items were developed to address one aspect of the coordination effort; that of improving the comparability of data items that are intended to measure the same behavior or concept across systems. The purpose of the core question items then, is to promote standardization of key items across disparate data systems so that minimal data needs of prevention planners and policies makers can be addressed.

Behavioral (and other) indicators are currently collected at the general population, infected population, and high-risk population levels. General population surveys typically have strong sampling methodology and provide results that are generalizable to the total population. They can measure the impact of prevention programs on the general population, and can provide a baseline with which to compare high risk samples. However, they provide limited information on relatively rare risk behaviors, particularly among high-risk subgroups such as men who have sex with men and injection drug users. Surveillance of infected populations yields information on risk for infection acquisition and ongoing transmission, but do not provide information on at-risk, yet uninfected populations. Surveillance among high-risk populations fills this void, but is often dependent on convenience sampling, and therefore limits the degree to which the results can be generalized. The necessary integration of data derived from these systems is often hampered by a lack of comparability between data items intended to measure the same behavior or concept. Use of the core questions as a common standard would allow for integration, and thus vastly improve the quality and quantity of information produced.

The core question items are not intended to serve as a complete, “off the shelf” survey. Rather, they suggest: (1) a standard question and response format for items, and (2) only those items that are considered to address minimal data needs, or “core” items. The items offered here are considered the basic and necessary components to be included in questionnaire-based measures of HIV Testing behaviors at the three population levels.

To allow for comparison across all three surveillance levels, but address only the minimal data needs for each, two “tiers” of questions were developed. The first tier questions are considered the minimal number of questions to be used in all surveys. These questions are suitable for general population surveys, and thus do not include questions of high-risk behaviors that are relatively rare among the general population. The second tier questions include the first tier, as well as additional questions that obtain more detailed information about high risk behaviors that are relevant to high-risk and infected populations. The additional items in the second tier are intended to address minimal data needs for high risk and infected populations.

The core question items are intended to be serviceable across a broad range of surveys with various objectives, target populations, and data collection settings, while maintaining a sound methodology and addressing the identified minimal data needs.

Even so, it is recognized that the questions are not capable of serving the specific purpose of every researcher. First, because the core questions address only minimal data needs, they consequently exclude an array of important questions and topics of interest to researchers. Second, the core items were developed to suit interviewer administration, and may need to be adapted for use in other settings (e.g., self-administered). It is also likely that the formatting (e.g., question order), or question wording may not suit the particular situation (e.g., for a jail or prison setting). It is also possible that only certain items from the second tier are relevant for the study.

Therefore, researchers are encouraged to add additional questions of interest, extract relevant portions when necessary, change the format, and otherwise adapt the core questions to suit the unique purpose of their study.

We hope that persons conducting studies will be able to adopt the questions we recommend. We realize that in some instances researchers may find it necessary to use a different form of a question, for example in order to maintain a continuous time series. In those cases we would urge the researchers to adopt both questions – this would have numerous advantages, allowing for internal as well as cross-study comparisons, and maintaining time series. The small number of basic core questions adds little additional cost, especially in light of the many benefits.

III. Development and Status

The methodology employed by the working group to develop the core measures can be best described as a modified Delphi approach and is comprised of the following iterative steps: 1) identification of existing surveys, questions, and relevant behavioral elements; 2) creation of a survey database; 3) review of published data or analyses of existing available data; 4) discussion of draft core questions; 5) distribution of draft questions to internal and external consultants to obtain feedback; 6) cognitive testing; 7) inclusion of core questions in existing surveys to obtain pilot data; 8) redrafting of questions on the basis of pilot data and feedback; 9) dissemination and support of core questions; 10) ongoing evaluation, feed-back, and adaptation of questions.

All of the core measures are developed and continually revised by this iterative process. The HIV Testing core measures offered here are currently under review. We encourage you to send your feedback on these questions to Danni Lentine (DLentine@cdc.gov), or join our discussion board conversation. Further refinements of the questions will be made based on this feedback, results of cognitive testing, and the results of pilot testing.

The working group identified and adopted the “critical event” concept to guide the development of all the core question items. Using the critical event approach, questions refer to the behavior of the respondent the last time the event occurred. The advantages of this approach include minimal recall bias and simple categorical (yes/no) responses. The disadvantage of using critical events is the potential of losing detail on less likely events. There again, researchers are encouraged to use additional questions that obtain the data of interest.

HIV TESTING QUESTIONS: FIRST TIER

I am going to ask about giving blood donations to a blood bank, such as the American Red Cross.

1. Have you donated blood since March 1985?

- | | | |
|------------|-----|---------------|
| Yes | [1] | |
| No | [2] | (skip to Q3b) |
| Refused | [7] | (skip to Q3b) |
| Don't know | [8] | (skip to Q3b) |

2. When was the last time you donated blood?

___ ___ / ___ ___ ___ ___

3a. The next questions are about the test for HIV, the virus that causes AIDS. Have you ever been tested for HIV, other than tests you may have had as part of blood donations?

- | | | |
|------------|-----|---------------|
| Yes | [1] | (skip to Q5a) |
| No | [2] | (skip to Q4) |
| Refused | [7] | (skip to Q8) |
| Don't know | [8] | (skip to Q8) |

3b. The next questions are about the test for HIV, the virus that causes AIDS. Have you ever been tested for HIV?

- | | | |
|------------|-----|---------------|
| Yes | [1] | (skip to Q5b) |
| No | [2] | (go to Q4) |
| Refused | [7] | (skip to Q8) |
| Don't know | [8] | (skip to Q8) |

4. I am going to read you a list of reasons why some people have not been tested for HIV. Which one of these would you say is the MAIN reason why you have not been tested? [Read responses indicated]

- | | |
|------|--|
| [01] | It's unlikely you've been exposed to HIV; |
| [02] | You were afraid to find out if you were HIV positive |
| [03] | You didn't want to think about HIV or about being HIV positive |
| [04] | You were worried your name would be reported to the government if you tested positive |
| [05] | You don't like needles |
| [07] | You don't trust the results to be confidential |
| [08] | You are afraid of losing job, insurance, housing, friends, family, if people knew you was HIV positive |
| [09] | You didn't know where to get tested or |
| [10] | Some other reason (specify_____) |

Do not read [77] Refused

Do not read [88] No particular reason

Do not read [99] Don't Know

(Now go to Q8)

HIV TESTING QUESTIONS: FIRST TIER

5a. When was the last time you were tested for HIV, other than tests you may have had as part of blood donations?

___ ___ / ___ ___ ___ ___

(Now go to Q6)

5b. When was the last time you were tested for HIV?

___ ___ / ___ ___ ___ ___

6. Not including your blood donations), which of these would you say was the main reason for your last HIV test? ? *[Read responses indicated]*

- [1] Just to find out/Worried that you are infected
- [2] Because a doctor, nurse or other health care professional asked you to
- [3] Because the Health Department asked you to
- [4] Because sex partner asked you to
- [5] For hospitalization or surgical procedure
- [6] To apply for health insurance or life insurance
- [7] To comply with guidelines for health workers
- [8] To apply for a new job
- [9] For military induction, separation, or during military service
- [10] For immigration
- [11] Because of pregnancy
- [12] Other reason - specify _____.
- [77] Refused
- [99] DK

HIV TESTING QUESTIONS: FIRST TIER

7. Where did you have your last HIV test? [If response is “at a clinic”, probe for type of clinic]

- [01] Private doctor/HMO
- [02] Counseling and testing site
- [03] Hospital (inpatient)
- [04] STD clinic
- [05] Family planning clinic
- [06] Prenatal clinic
- [07] Tuberculosis clinic
- [08] AIDS/infectious disease clinic
- [09] Military clinic
- [10] Insurance clinic
- [11] Employer clinic
- [12] Community health clinic or public health clinic
- [13] Outpatient hospital clinic or ER
- [14] Correctional facility (jail or prison)
- [15] Drug treatment facility
- [16] At home, with a home test kit
- [17] At home, by nurse or health care worker
- [18] Other location (specify_____)
- [77] Refused
- [99] Don't Know

8. How likely is it that you will get tested in the next year? Would you say:

- [1] Very likely
- [2] Somewhat likely
- [3] Somewhat unlikely
- [4] Very unlikely

*******END OF FIRST TIER QUESTIONS*******

Version 9.00: September 26, 2000
HIV TESTING QUESTIONS: SECOND TIER

I am going to ask about giving blood donations to a blood bank, such as the American Red Cross.

1. Have you donated blood since March 1985?

- | | | |
|------------|-----|---------------|
| Yes | [1] | |
| No | [2] | (skip to Q2a) |
| Refused | [7] | (skip to Q2a) |
| Don't know | [8] | (skip to Q2a) |

2. When was the last time you donated blood?

___ / ___

(If in past 12 months ask 2aa; otherwise go to 2a.)

2aa. Was one of your reasons for donating blood because you wanted to be tested for HIV, the virus that causes AIDS?

- | | | |
|------------|-----|-----|
| Yes | [1] | |
| No | [2] | |
| Refused | | [7] |
| Don't know | [8] | |

Sometimes people donate or sell blood or plasma at commercial plasma centers; that is a place where they will pay you for donating.

2a. Have you sold blood or plasma at a plasma center since March 1985?

- | | | |
|------------|-----|--------------------------------------|
| Yes | [1] | (ask Q2) |
| No | [2] | (if Q1 is yes, ask Q3a, if not, Q3b) |
| Refused | [7] | (if Q1 is yes, ask Q3a, if not, Q3b) |
| Don't know | [8] | (if Q1 is yes, ask Q3a, if not, Q3b) |

2. When was the last time you sold blood or plasma?

___ / ___

The next questions are about the test for HIV, the virus that causes AIDS. This usually involves a blood test, but could have involved a saliva test?

3a. Have you ever been tested for HIV, other than tests you may have had as part of blood or plasma donations?

- | | | |
|------------|-----|---------------|
| Yes | [1] | (skip to Q5a) |
| No | [2] | (skip to Q4) |
| Refused | [7] | (skip to Q8) |
| Don't know | [8] | (skip to Q8) |

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HIV TESTING QUESTIONS: SECOND TIER

3b. Have you ever been tested for HIV?

- | | | |
|------------|-----|---------------|
| Yes | [1] | (skip to Q6a) |
| No | [2] | (go to Q4) |
| Refused | [7] | (skip to Q8) |
| Don't know | [8] | (skip to Q8) |

4. I am going to read you a list of reasons why some people have not been tested for HIV. Which one of these would you say is the MAIN reason why you have not been tested? [Read responses indicated]

- [01] It's unlikely you've been exposed to HIV;
- [02] You were afraid to find out if you were HIV positive
- [03] You didn't want to think about HIV or about being HIV positive
- [04] You were worried your name would be reported to the government if you tested positive
- [05] You don't like needles
- [07] You don't trust the results to be confidential
- [08] You are afraid of losing job, insurance, housing, friends, family, if people knew you was HIV positive
- [09] You didn't know where to get tested or
- [10] Some other reason (specify_____)

Do not read [77] Refused

Do not read [88] No particular reason

Do not read [99] Don't Know

5. Has anyone ever recommended that you get an HIV test?

- | | | |
|------------|-----|---------------|
| Yes | [1] | |
| No | [2] | (skip to Q14) |
| Refused | [7] | (skip to Q14) |
| Don't know | [8] | (skip to Q14) |

5a. Who recommended you get a test? [Read responses indicated]

- | | |
|--|----------------------------------|
| [01] Doctor/nurse/other health care professional | [06] A friend or relative |
| [02] Sex partner | [07] Someone else [specify_____] |
| [03] Someone at health department | [77] Refused |
| [04] An outreach worker | [99] Don't know |
| [05] Drug sharing partner | |

(Now skip to Question 14)

HIV TESTING QUESTIONS: SECOND TIER

6a. When was the last time you were tested for HIV, except for tests you may have had as part of blood or plasma donations?

___ ___ / ___ ___ ___

6b. When was the last time you were tested for HIV?

___ ___ / ___ ___ ___

7. In the past year, how many times have you been tested for HIV, including times you did not get your results?

___ ___ ___ times

8. Not including your blood donations), which of these would you say was the main reason for your last HIV test?

- [1] Just to find out/Worried that you are infected
- [2] Because a doctor, nurse or other health care professional asked you to
- [3] Because the Health Department asked you to
- [4] Because sex partner asked you to
- [5] For hospitalization or surgical procedure
- [6] To apply for health insurance or life insurance
- [7] To comply with guidelines for health workers
- [8] To apply for a new job
- [9] For military induction, separation, or during military service
- [10] For immigration
- [11] Because of pregnancy
- [12] It was part of a research study
- [13] Other reason - specify _____.
- [77] Refused
- [99] DK

HIV TESTING QUESTIONS: SECOND TIER

9. Where did you have your last HIV test? [If response is "at a clinic", probe for type of clinic]

- [01] Private doctor/HMO
- [02] Counseling and testing site
- [03] Hospital (inpatient)
- [04] STD clinic
- [05] Family planning clinic
- [06] Prenatal clinic
- [07] Tuberculosis clinic
- [08] AIDS/infectious disease clinic
- [09] Military clinic
- [10] Insurance clinic
- [11] Employer clinic
- [12] Community health clinic or public health clinic
- [13] Outpatient hospital clinic or ER
- [14] Correctional facility (jail or prison)
- [15] Drug treatment facility
- [16] At home, with a home test kit
- [17] At home, by nurse or health care worker
- [18] Other location (specify_____)
- [77] Refused
- [99] Don't Know

10. Did you get the results of your last test?

- Yes [1]
- No [2]
- Refused [7]
- Don't know [8]

11. The last time you were tested for HIV, were you asked to give your first and last name?

- Yes [1]
- No [2]
- Refused [7]
- Don't know [8]

12. The last time you were tested for HIV, which of the following types of HIV test was used?

Was it: [Read all response options]

- A blood test, and you had to return in a few weeks for the results [1]
- A blood test, and you got the results within 24 hours [2]
- A saliva test, where you or someone else took a swab from your mouth. [3]
- A urine test [4]
- A home test kit, where you used a self-sampling kit to get a blood sample [5]
- Or some other type of test (specify_____)[6]

HIV TESTING QUESTIONS: SECOND TIER

13. A positive HIV test means you have the virus that causes AIDS. Have you ever tested positive for HIV?

Yes	[1]	(END)
No	[2]	
Refused	[7]	
Don't know	[8]	

14. How likely is it that you will get tested in the next year? Would you say:

Very likely	[1]
Somewhat likely	[2]
Somewhat unlikely	[3]
Very unlikely	[4]

*****END OF SECOND TIER QUESTIONS*****